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ABSTRACT

Characteristics of the older developmentally disabled adult were studied in an examination of data collected on 485 randomly selected clients in four age categories; 18 and under (N=74), 19-54 (N=336), 55-64 (N=48), and 65 and over (N=27). Medical and physical problems were assessed, including general health, mobility problems, and prescription of medications. Among clients ages 65 and over, 50% were classified as having a life-threatening physical condition, compared to 11% of clients aged 55-65 and 6% of those under 54. The highest percentage of mobility problems occurred in the under-18 and over-65 age groups. Antipsychotic drugs were prescribed for 54% of clients over age 65. After age 65, decided decrements were observed in independent functioning, physical development, self-direction, and socialization. Clients in this age group also lived in the most restricted residential environments. Significant increases were noted in the upper two age groups in self-abusive behaviors and hyperactive tendencies, as measured by Part II of the Adaptive Behavior Scale. Additional results are presented, and the interpretation and implications of data are discussed in terms of programming for older developmentally disabled adults. References and tables are appended. (JW)

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THE OLDER DEVELOPMENTALLY DISABLED CLIENT

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The older developmentally disabled person has been characterized as belonging to the "invisible group." Little research has been conducted on developmentally disabled persons older than 50 years of age and few specialized services for this population are available. However, there are many reasons why such little attention had been focused on this group. First among these is the fact that historically the life span of mentally retarded clients was shown in several studies to be much shorter. Kaplan studied the Sonoma Home in California from 1917 to 1939 and found the average lifespan to be 26.6 years. Only 15% of residents lived past 50 years. A more comprehensive recent review by Carter and Jancar (1983) reported that between 1931 and 1935 the mean age that institutional clients died was at 18.5 while between 1976 and 1980 this mean age had risen to 59.1. An even more dramatic increase was evident for individuals with Down's Syndrome -- a rise from 11.0 years in 1931-35 to 54 years between 1976 and 1980.

Using the stated prevalence rate of 3% of the population, Seltzer and Seltzer (1984) estimated that there are between 1 million and 1.380 million older developmentally disabled persons.

There is some evidence that Down Syndrome and Alzheimer's Disease (senile dementia) may be linked together. Malamud (1964) found that all Down Syndrome individuals whom he studied showed signs of this early aging after 35 years of age. Wisniewski and colleagues (in press) found typical tangles, plagues and densities of Alzheimer's in all of 49 cases studied post mortem who were 30 years and older.

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Janicki and MacEachron (1984) remarked recently that "there has been limited information regarding the health status of elderly individuals with mental retardation." The largest epidemiological study of older clients was conducted by Jacobsen and Janicki (1983) in N.Y. State. They found that by the time a client reached "old age", 73 years and over - the majority suffered from cardiovascular disease, had a sensory deficit (e.g. deafness), and increases were reported in the incidence of respiratory problems. Muscularskeletal disorders were also more common among these older individuals - - about 1/3 of those over 73 had such disorders. In the few studies which have addressed the physical status of older developmentally disabled persons, when compared to normal individuals, mentally retarded individuals over 50 years of age were more likely to have seizures and deafness and less likely to have cardiovascular disease (Anglin, 1981). The Seltzers together with Sherwood (1982) reported increased incidences of seizures, Parkinson's Disease, multiple sclerosis, and respiratory problems among mentally retarded clients. However, in looking at only developmentally disabled persons, older clients had significantly fewer seizures (Janicki & MacEachron, 1984) than younger ones. Medication usage is also high among older developmentally disabled individuals -- 61% between the ages of 63 and 72 and 69% of those over age 72.

The Seltzers and Sherwood (1982) also looked at differences in community adjustment of 25 deinstitutionalized mentally retarded adults over 55 years of age as well as 128 younger deinstitutionalized adults. Even though there were no differences in intellectual ability, number of medical problems or level of retardation, there were large deficits in the adjustment of these older clients. The older group had mastered significantly fewer of the skills needed to live in the community. They also performed the community living skills they had mastered significantly less often. Finally, they demonstrated less motivation to perform the tasks which would be required if they were to continue living independently in the community. One glaring difference between these age groups was their living arrangements. While 18% of the younger deinstitutionalized individuals were living independently, no older clients did. Sixty-eight percent of these older clients resided in foster homes -- only 15% of the

younger group lived in this type of residence. Another obvious difference was the larger network of social support in the community for the younger client. As an individual ages, his or her need for auxiliary services increases. If these services are not provided, the chances are this client will be moved to an environment which will supply them -- quite probably a more restrictive nursing home.

Cotton and fellow researchers (1981) compared 25 mentally retarded individuals in nursing homes, 25 non-handicapped elderly persons in nursing homes and 25 non-handicapped individuals in the community. The medical status of normal older individuals in nursing homes was more than twice as poor as developmentally disabled persons in the nursing home. Their medical problems represented a nine-fold increase over their community based peers. Using the Geriatric Rating Scale that measured level of functioning and the Fairview Self-Help Scale that measured motor dexterity, social interaction, and self-help skills, developmentally disabled and normal older individuals in nursing homes mirrored each other -- aged in community scores reflected twice those of the other two groups.

The Missouri Institute of Psychiatry has supported research conducted by the University Affiliated Facility at the University of Missouri-Kansas City which has looked at the fit between the needs of developmentally disabled persons and the services provided by the residential facilities in which they live. The data reported here were gathered about three years ago during that study. Four hundred eighty-five subjects (268 males and 217 females) were randomly selected from the computerized files of the Missouri Department of Mental Health/Division of Mental Retardation/Developmental Disabilities. Male clients under the age of 55 outnumbered females. (62% of clients 18 and under were male). (See Table 1.) However, there was a reversal in older age groups -- 67% of clients 65 and over were female. This preponderance of females in the older group mirrors the normal population. Old age was categorized in a manner similar to that of Jacobson, Sutton, and Janicki's study (1985) in which an "aging mentally retarded person" was considered to be between 55 and 64 years of age, and an "elderly mentally retarded person" 65 years of age and older. Approximately 10% of the population in our Residential Placement Study were

between the age of 54 and 64. Six percent represented the ages of 65 and over.

Approximately 35% of clients 65 years of age and over resided in skilled nursing homes or intermediate care facilities -- considered to be the most restrictive of the Missouri Division of Mental Retardation/ Developmental Disabilities' residential environments. Only 15% of those persons between 19-54 had this living arrangement. (See Table 2).

The medical and physical needs of these clients were compared. (See Table 3.) Case managers of clients placed in the community and unit personnel for institutionalized clients responded to a Medical/Physical Needs Assessment Form. There were no differences between age groups in the number of clients who needed assistance because of blindness or deafness -- common among older persons in general. The percent of clients for each age group who experienced seizures was also not significantly different. About 33% of clients under 55 had seizures. This decreased to about 20% for the oldest group.

Survey questions were also asked regarding the mobility problems of clients. While there were no significant differences between groups, the highest percent of problems occurred in the under 18 and over 65 age groups. These same groups required significantly more help with assistive devices. However, prostheses were significantly more common in the oldest group (low of 9% for the youngest clients to 17.4% for those over 65 years of age). These statistics mirror those of Janicki & Jacobsen in N.Y.

The amount of care in performing daily tasks was also examined. Twice as many clients 65 and over required assistance in bathing and dressing than did those between 54 and 64. A larger increase occurred in toileting needs. Only 9% of the 55-64 age clients required assistance, while almost 22% over 65 did. The need for help with eating actually decreased with age.

Where the differences become very significant are in answers to survey questions such as "Does the client have a diagnosed condition which may be life threatening -- as heart, lung, liver or kidney problems?" Only about

6% of those under 54 years were classified as having a life threatening problem. This increased to 11% for clients between 55 and 65. However, for clients over 65, this rate increased to 50%. Approximately half of these problems in these older clients required at least daily monitoring. The percentages for the other age groups was less than 5%. Thus, the older client requires considerably more nursing attention.

There were however, no significant differences between groups in the percent that were bedridden -- 5% or less for each group.

Typically, an older population is prescribed more medications than a younger one. That was also observed in our study. While 54% of young clients received some form of medication, 97% of clients over 65 (all clients except one) received drugs. The administration of multiple drugs in this age group has been cited in the medical literature as a potential problem in light of the possible interaction between the various chemical actions of medications. In our sample, 22% of those over 65 received a combination of five or more types of drugs. These medication statistics mirror most of the surveys reported in the literature (Intagliata & Rinck, 1985; Lipman, 1970; Silva, 1979).

A more disquieting statistic was found while examining the prescription of psychotropic medication. For fifty-two percent of clients over 65 years of age as antipsychotic drugs were prescribed. This is quite significant, since there is evidence in the American Psychiatric Association (APA) literature that these medications in older persons may produce an possible irreversible side effect -- tardive dyskinesia. An A.P.A. task force this year urged its members to be cautious in prescribing neuroleptics for elderly individuals since "at least 40% of elderly, chronically institutionalized patients or outpatients exhibit more than minimal signs of probable tardive dyskinesia."

There is also an increase in the number of antidepressive medications prescribed. While no clients under 18 received this medication, 13% of those over 65 were so prescribed. Since antidepressive medication can be useful, not only for depression, but also for enuresis and for pain con-

trol, more investigation should be conducted before conclusions about this increase are made.

Comparisons were made between these four age groups with clients' decile scores on the A.A.M.D. Adaptive Behavior Scale. (See Table 4.) An overall MANOVA found highly different scores between age groups for both the Part I -- Functional Skills section and the Part II -- Maladaptive Behaviors section. There were significant differences on nine out of 13 of the subscales on Part II (Maladaptive Behaviors) of the A.B.S.

There is also a significant increase in violent and destructive behavior between the upper two age groups ($F(3,464) = 2.54$, $p < .05$). Clients between 55 and 64 were .5 decile score below that of those over 65. This subscale includes items such as threatening or performing physical violence, damaging others' property, and exhibiting a violent temper or temper tantrums. The older age groups (above 55) exhibited significantly more self-abusive behavior, too ($F(3,464) = 6.19$, $p = .001$). Scores for this subscale were relatively stable (about 7.5) until age 55 when there was a significant increase (to over 8.06 points). Similarly, sexually aberrant behavior increased significantly after 55 years of age ($F(3,464) = 2517$, $p < .001$).

The fourth subscale (trustworthiness) shows incremental changes at the age of 55. This subscale measures the client's taking property without permission and lying and cheating behaviors. There is a linear increase in this subscale. Before 18 the scale score is 5.76. Between 19 and 54 this increases to 5.94. However, after 55 there is a jump to 6.46.

Hyperactive tendencies are defined in the ABS as talking excessively or moving or fidgeting constantly. There was a large and significant increment in these scores after the age of 55 ($F(3,464) = 20.29$, $p < .001$). Adult clients below 55 had an average score of 7.17 in this category. However, above 55 the scores means increased to 8.00.

Clients over the age of 65 clearly showed significant increments in maladaptive behavior on several scales. Withdrawal was exhibited by these older clients, as well.

Subscales which measured antisocial behavior also demonstrated that these older clients were regarded as having more difficulties than younger clients ($F(3,464) = 3.55$, $p = .014$). The antisocial scale asks questions about the client's teasing, manipulating others, disrupting activities, being inconsiderate of others, showing disrespect for others and using angry language. While clients between the age of 19 and 64 maintained a mean score of 5.52, it increases to 5.95 for the group of clients who are over 65 years of age.

Rebellious behavior showed similar significant increments ($F(3,464) = 8.96$, $p<.001$). This category investigates the client's attitudes toward regulations, following instructions, attitudes toward authorities, attendance at required activities, running away and misbehaving in group settings. Clients between 19 and 64 have almost identical means (6.31 and 6.21). However, for those above age 65, the mean increases to 7.04 which is significant at the .001 level.

While inappropriate interpersonal manner showed an improvement between 55 and 64 years of age, there was a decrement after age 65 ($F(3,464) = 20.98$, $p <.001$). This scale measures social behaviors such as blowing on others' faces, burping, kissing and hugging others, touching inappropriately or hanging on to others and not letting go.

Four of the subscales of Part I -- the Function Skills section of the ABS -- show significant decrements for clients over the age of 65. The Independent Functioning subscale showed increments in scores up to the age of 65 from a low of 2.32 for those under age 18 to 3.54 for the group aged 55-64. However after 65, this score decreases precipitously to 1.70 ($F(3,484) = 3.61$, $p = .013$). Similarly the physical development scale increases through the age of 65 (from 3.51 to 4.85) ($F(3,484) = 3.65$, $p = .013$), at which point there is a large decrement to 2.44.

The items on the self direction scale ask questions about the initiative of the client, his or her passivity, how much persistence they maintain during activities and how well they organize their leisure time. Older clients have the lowest scores on this subscale (decreasing from 3.47 for ages 55-64 to 2.03 for the group that is over 65 years of age ($F(3,479) = 17.17$, $p = .03$).

A very important item, socialization, also reflected large decreases for the older groups ($F(3,479) = 3.23$, $p = .02$). Socialization is defined by the ABS as cooperation, consideration for others, awareness of others, interaction with others, participation in group activities, selfishness and social maturity. Scores increase from the youngest group through 64 years before they drop to this low of 3.41.

In summary, we found that up to age 65 there were no decrements in functional behavior -- in fact increases in many of the scales. After age 65 there were decided decrements in independent functioning, physical development, self-direction and socialization. These older developmentally disabled clients also resided in the most restrictive of the Division's residential environments. They also showed significant increases in maladaptive behavior on 9 of the 13 subscales on Part II of the ABS.

Why do we see this profile? There are several possibilities: First, this may merely be reflective of the "normal aging pattern." As this was not a longitudinal study, we can not really say anything about this yet. We hope to have three year follow-up data in a few months. Second, the effects of institutionalization may be reflected in our data. This group did not have the programs and services available to them as many clients may have access to today at an earlier age. Third, there may be a significant lack of programming opportunities for these individuals. Since this group resided in what was felt to be the least restrictive environment for them, the question arises as to the type of programming they were receiving. This study did not have access to their individual habilitation plans, nor were we privy to information about their programming activities. Future research should focus on these areas in relationship to these

exhibited decrements in functional skills and increments in maladaptive behavior.

We suggest that the least restrictive environment be maintained for these clients as long as possible. While a majority of this population is reported to have life threatening conditions, few are bedridden. If visiting nurses or other generic services were available to these older persons, this might enhance their life opportunities and their adjustment to old age. It would be tragic to relegate these individuals to what all too often are the sterile environments of nursing homes, if other more "engaging" environments that reflected less restrictive alternatives were made available.

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TABLE 1

SEX AND AGE OF CLIENTS

AGE CATEGORIES	SEX				TOTAL	
	MALE		FEMALE			
18 AND LESS	46	(62%)	28	(38%)	74	(15%)
19-54	190	(57%)	146	(43%)	336	(69%)
55-64	23	(48%)	25	(52%)	48	(10%)
65 AND OVER	9	(33%)	18	(67%)	27	(6%)
TOTAL	268		317		485	

TABLE 2

TYPES OF FACILITIES IN WHICH EACH AGE GROUP RESIDED

	Age Group			
	18 & less	19-54	55-64	65+
Skilled Nursing or Intensive Care Facility	2 (3.4)	28 (15.6)	9 (29.0)	7 (35.0)
Adult Boarding or Residential Care Facility	12 (20.7)	73 (40.5)	13 (42.0)	10 (50.0)
Residential Learning Center	15 (25.9)	18 (10.0)	0 (0.0)	0 (0.0)
Foster Care	9 (15.5)	8 (4.4)	0 (0.0)	2 (10.0)
Group Care Home	20 (34.5)	50 (27.8)	8 (25.3)	1 (5.0)
Semi-independent Apartment	0 (0.0)	3 (1.7)	1 (3.2)	0 (0.0)

$X^2 = 59.24$ (15), $p < .0001$

TABLE 3

DEVELOPMENTAL COMPARISON OF MEDICAL/PHYSICAL NEEDS

Subscale	18 and Less (80)	19-54 (318)	55-64 (42)	65+ (23)	
Require Assistance with Mobility	27.5	17.6	11.9	21.7	
Dressing	38.8	24.2	14.3	26.1	*
Toiletting	37.5	21.7	9.5	21.7	**
Eating	32.5	15.7	7.1	4.3	***
Bathing	40.0	25.2	14.3	30.4	**
Special Equipment	28.8	14.2	9.5	21.7	**
Requires Prothesis	8.8	5.9	11.9	17.4	*
Colostomy	0	.3	2.4	8.7	***
Bedridden	5.0	2.5	0	4.3	*
Deaf	5.0	3.8	2.4	4.3	
Blind	8.8	5.7	4.8	8.7	
Needs Assistance Frequently	2.5	0	0	0	
Needs Assistance Occasionally	1.3	.6	7.1	8.7	
Seizures Present	31.3	33.3	21.4	17.4	
Presence of Life Threatening Disease	6.3	6.9	11.9	52.2	***
Condition Requires Daily Monitoring	3.8	3.8	4.8	21.7	***
Weekly Monitoring	0	2.5	4.8	26.1	***
Dental Problems Requiring Attention	6.3	6.0	11.9	21.7	*
Requires Special Diet	26.3	35.8	26.2	34.8	
Requires Services of Dietician Daily	13.8	25.8	14.3	30.4	*

TABLE 4

DEVELOPMENTAL COMPARISON OF DECILE SCORES ON THE ADAPTIVE BEHAVIOR SCALE

Subscale	Age Groups: Less than 18	19-54	55-64	65+
Part I - Functional Behavior				
Independent Functioning	2.32 (74)	2.57 (336)	3.54 (48)	1.70 ** (27)
Physical Development	3.82	3.51	4.85	2.44 **
Economic Activity	4.59	4.84	4.84	3.70
Language Development	3.39	3.28	4.27	2.89
Numbers and Time	4.42	3.83	4.54	3.59
Domestic Activity	4.38	4.19	4.71	2.92
Vocational Activity	4.30	3.73	4.38	3.56
Self-Direction	2.75	2.49	3.48	2.04 *
Responsibility	4.75	4.80	5.50	4.03
Socialization	3.69	4.08	5.48	3.41 *
Part II - Maladaptive Behavior				
Violent and Destructive Behavior	5.67	5.75	4.94	5.48 *
Antisocial Behavior	4.63	5.51	5.52	5.95 *
Rebellious Behavior	5.07	6.31	6.21	7.04 ***
Untrustworthy Behavior	5.76	5.94	6.46	6.56 **
Withdrawal	6.02	6.64	6.40	7.00 **
Stereotyped Behavior	7.00	7.25	7.33	7.19
Inappropriate Interpersonal Manners	6.44	7.40	7.29	7.41 ***
Unacceptable Vocal Habits	6.83	7.50	7.46	7.23 ***
Unacceptable Eccentric Habits	6.91	7.15	7.00	7.04
Self-Abusive Behavior	7.49	7.82	8.06	8.11
Hyperactive Tendencies	6.87	7.62	8.27	8.26 ***
Sexually Aberrant Behavior	6.70	7.17	8.10	8.00 ***
Psychological Disturbances	5.32	5.46	5.40	6.41

Significance Levels

* p = <.05
** p = <.01
*** p = <.001

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